

Questionnaire on the right of persons with disabilities to the highest attainable standard of health

1. Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.

This question can be answered by the Ministry of Human Capacities.

2. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general, as well as with particular focus in the following areas:

It is primarily KSH (the Hungarian Central Statistical Office) and EMMI (Ministry of Human Capacities) that can provide information on statistical data.

- Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities;
 - Barrier-free accessibility is achieved very slowly, only through refurbishments. In the case of newly built real estate properties, barrier-free accessibility is a fundamental requirement but unfortunately, uniform design has not been adequately realized as yet. Barrier-free accessibility in our days rather means making the buildings designed for the needs of the members of the majority society utilizable for persons with disabilities by applying "supplementary solutions", there is no paradigm shift at this stage.
 - It is typical of developing barrier-free accessibility that it mostly focuses on persons with reduced mobility, while those who are deaf and hard of hearing, or those who are blind and partially sighted are usually only provided with partial solutions, which do not result in the complete realization of the right to self-determination of those who are affected.

- Those with intellectual disabilities are in an even more difficult situation, there are very few information leaflets with easy to understand content for those with disabilities, and it happens in many cases that the staff have no time to provide the tailor-made information required by the Health Care Act to those affected.
- The right to information is violated in many cases due to the institution of guardianship too, information is often only provided to the guardian, who is authorized to give consent, despite the respective statutory requirement.
- The report of the Commissioner for Fundamental Rights No. AJB-437/2018 was launched on the basis of a complaint, in which it was reported that patient care attendants do not transport the electric wheelchairs along with the patients. As a consequence of this, however, no wheelchairs are available for the patients time of their transportation hospital/doctor, without which those affected cannot be mobile, this is why it happens that they have to sit still for several hours in the corridors of the health care facilities and without their wheelchairs, they cannot even relieve themselves during their waiting time, they cannot go to the bathroom, they cannot get themselves anything to eat or drink, for example. The report also mentioned that the affected persons mostly have appointments at these facilities but it happens many times that they are served only after lengthy waiting times.

The petitioner complained that according to the relevant law, the transportation obligation of the service providers who transport patients only extends to lightweight, collapsible wheelchairs, together with the patients but not to electric wheelchairs.

The Ombudsman requested the Minister of Human Capacities to

- o consider, with regard to the content of the report, by involving the State Secretariat for Health Care, through the amendment of NM (Ministry of Welfare) decree No. 19/1998. (VI.3.) on Patient Transportation, allowing that other types of wheelchairs used by the affected persons can also be transported in patient transport vehicles, besides the lightweight, collapsible wheelchairs;
- o assess, in cooperation with the Minister for the National Economy, the head of the National Ambulance Service, as well as the patient

transport organizations funded by the National Health Insurance Fund, the required financial and infrastructural resources and potentials.

It is the Ministry of Human Capacities that can provide further information on what measures have recently been taken for establishing the statutory and financing conditions of equal access to health care services of persons with reduced mobility using electric wheelchairs.

 access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage;

As a result of the joint EU action on the shift to community psychiatry concluded on December 31, 2016 (Joint Action on Mental Health and Well-being – Towards community-based and socially inclusive mental health care – Situation analysis and recommendations for action), the following was established with respect to Hungary:¹

- there is no special regulation and allocated budget in place for community psychiatry services;
- within the field of mental health treatments, the place, role and establishment of community facilities are not clarified on the level of the law;
- the cooperation between the social and health care systems is unsatisfactory and dysfunctional with regard to community psychiatry services;
- the regulation, management and managing bodies of the social and health care sectors are different;
- there is no guidance as to the transformation;
- there are serious deficiencies in human resources (including the low number of psychiatrists and experienced social workers in community psychiatry services);
- there is a limited availability of community psychiatry services in the countryside, the infrastructure, the professional staff and financing are deficient.

There are very few psychiatrists working in the state social welfare system, and the private experts are not affordable to everybody. There is an even more serious deficiency of experts in the field of child and adolescent psychiatry.

¹ Mental Health and Wellbeing Report - p. 113; http://www.mentalhealthandwellbeing.eu/assets/docs/publications/WP5%20Final-20151203075843.pdf

The Commissioner for Fundamental Rights issued a report on the access of HIV/AIDS patients to non-discriminatory health care services under number AJB-1026/2012. The report was launched on the basis of a complaint, which contained that HIV/AIDS patients are regularly exposed to the violation of their rights when they wish to use health care services for a reason other than a health condition related to their infectious disease. The practice that has evolved is that after the affected patients reveal that they are infected with HIV, as it is their statutory obligation to do so, health care services are often denied from them and most of the time they are directed to a central health care facility in the capital city. This on the one hand incurs unjustified costs and missed work time, on the other hand, makes the process of providing health care services to these patients longer.

The Equal Treatment Authority launched a procedure against the Central Institute of Stomatology and they condemned the practice followed by the institute regarding their discriminatory practices against HIV and AIDS patients on March 26, 2013.

Then, in the same year, the State Secretary for Health Care at the Ministry of Human Capacities published an information material for the health care staff on the health care serviced to be provided to HIV-infected patients.

• access to free or affordable disability-specific healthcare services and programmes; and

We have no information on this.

 access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention.

There are problems in this area. The state-funded medical aids are not necessarily products of the highest quality. It is a further issue that for certain persons, the simultaneous use of several medical aids would be necessary, however, the simultaneous state-funded use of these is not allowed by the financing regulations.

3. Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.

We have no information on this.

4. Please provide information on the observance of the right to free and informed consent of persons with disabilities

regarding healthcare, including sexual and reproductive health and mental health services.

- There are very few easily accessible information materials for those with intellectual disabilities, and many times, the health care staff have no time to provide the tailor-made information required by the Health Care Act to the patients.
- The right to information is violated many times due to the institution of guardianship as well, the information is often provided only to the guardian who is authorized to give consent, despite the respective statutory requirement.
- Section 13 of the Health Care Act contains the following relevant provisions related to the right to information:
- 13 (1) A patient is entitled to receive comprehensive tailormade information.
- (2) A patient is entitled to receive detailed information on
- a) their health condition, including the respective medical opinion,
- b) the recommended examinations and interventions,
- c) the possible benefits and risks of the performance or absence of the recommended examinations and interventions,
- d) the planned dates of performing these examinations and interventions,
- e) their right to decide on the recommended examinations and interventions,
- f) the possible alternative procedures and methods,
- g) the process and expected outcome of the medical service to be provided,
- h) any further care to be provided, as well as
- i) the recommended lifestyle.
- (3) A patient is entitled to ask further questions during and after the information session.
- (4) A patient is entitled to become aware of the outcome, the possible failure of the individual examinations and interventions, or any outcome that is different from expected, as well as the reasons therefor, during their medical treatment.
- (5) A patient who is incapacitated, a minor with limited capacity, and a patient with partially limited capacity with regard to any type of condition are also entitled to receive information suited to their age and mental state.
- (6) A patient is entitled to be familiar with the names, qualifications and positions of the persons who are directly involved in the medical care provided to them.
- (7) It is the supervising authority that shall provide the conditions required for exercising the rights to information.

- (8) A patient is entitled to receive clear information, taking into account their age, level of education, knowledge, state of mind, their wish in this respect, as well as that if needed and if possible, to use an interpreter or a sign interpreter for providing such information.
- (8a) If a patient has a supporter in making his health care related decisions according to the Act on Supported Decision-making, the attendance of such supporter shall be ensured at the request of the patient, during the information session.
- (9) Prior to the examination, the physician shall inform the patient, as long as this is allowed by the latter's condition, on that the fee of the examination and the subsequent care should be reimbursed if there is no urgent need on the basis of the outcome of the examination and if the costs of the health care service are not covered in the state budget and the National Health Insurance Fund of Hungary either.
- 14 (1) A capacitated patient may relinquish such information, except if they should be aware of the nature of their disease in order to avoid jeopardizing the health of others. If the intervention takes place at the patient's initiative and for a purpose other than a therapeutic one, relinquishing such information shall only be valid if it happens in writing.
- (2) The provisions set out in Section (1) shall also be applied in the case of minors over the age of 16.
- (3) A patient has a right to information even if their consent is otherwise not the precondition to starting the medical treatment.

A relevant provision related to the right to self-determination:

- 15 (1) A patient has the right to self-determination, which can exclusively be restricted in cases and in a way defined by law.
- (2) In the framework of exercising the right to selfdetermination, a patient may freely decide whether they would like to use a health care service, and in the course of these services, which interventions they give their consent to, and which they refuse, with regard to the restrictions required by Section 20 (see below).
- (3) A patient is entitled to be involved in the process of decision-making concerning their examination and treatment. Apart from the exceptions in this law, it is a precondition to performing any medical intervention that the patients give their informed consent to it, free of any misleading, threat or coercion (hereinafter referred to as: consent).
- (3a) If the patient has a supporter in making his health care related decisions according to the Act on Supported

Decision-making, it shall be ensured, at the request of the patient, that the supporter be present when giving consent, and that the supporter has the opportunity to coordinate the decision with the patient, by adhering to the provisions set out in Section 27.

The right to refuse treatment:

- 20 (1) Capacitated patients, with regard to the provisions set out in Sections (2)-(3) and with the exception of the case in Section (6), are entitled to refuse treatment, except if the lack of such treatment would jeopardize the life or physical integrity of others.
- 21 (1) In the case of a patient who is incapacitated, a minor with limited capacity, and a patient with partially limited capacity with regard to exercising their right to health care services, the medical treatment as per Section 20(2) shall not be refused.
 - As it is also pointed out in the Ombudsman's report No. AJB-344/2018, in the case of those persons with (psycho-social) disabilities who are quardianship, it is necessary to obtain a more thorough understanding of the intentions of the wards and to support the dependents on this basis, with regard to the fact that the institution of guardianship as a supplementary rather than supporting kind of institution, pretty much runs counter to the spirit of CRPD and the provisions set out therein. It is by putting supported decision-making² as the type of solution that reflects the approach represented by CRPD into the foreground that the treatment of persons with disabilities should be resolved.

In Hungary, a guardian may ask that an incapacitated patient or a patient with limited capacity be admitted to a psychiatry department, however, in such a case, the court is obliged to hold an on-site review, and to make a decision on the lawfulness of the admission and the maintenance of the medical treatment.

In the case of a minor with limited capacity, a patient with partially limited capacity with regard to exercising their right to health care services, or an incapacitated patient, such patient may be subjected

² Section 2:38 of the Hungarian Civil Code (Ptk), Act CLV of 2013, Chapter XVI/A of government decree No. 149/1997 (IX.10.), Section 65/C of the Civil Procedure Act (Pp). In Section 2:38 of the Hungarian Civil Code (Ptk), the new legal institution of supported decision-making is regulated in order to avoid the limitation of capacity but as supported decision-making does not affect the capacity of the person concerned, and the Hungarian Civil Code does not provide on the detailed rules of supported decision-making, it is Act CLV of 2013 that regulates this.

to institutionalized psychiatric treatment at the request of the legal representative/guardian. In such cases, the court has to examine, ex officio, whether the institutionalized medical treatment is justified or not.

5. Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of health policies, programmes and services.

We have no information on this.